Caregiving Families:
A Team Approach To Lessen The Burden
Faculty/Presenter Disclosure

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Relationships with financial interests:

  Kim Crowe: Employee of Covenant Health, Tertiary Palliative Care Unit
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None

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None
Mitigating Potential Bias

- Not Applicable
Objectives

• Identify and define what creates challenges and complexities within the family system

• Explain approaches and strategies used by a palliative care team to navigate the challenges of caregiving

• Describe the ethical and moral dilemmas faced by staff when caregiving

• Show how the use of specific skills, tools, and region-wide resources help in providing quality palliative care, that you can apply to your own practice
What Is A Family?

There is no globally “accepted” definition of a family.

The family is a “natural and fundamental group unit of society” according to the UN Human Rights Council, 2016.
Definition of Palliative Care

• WHO Definition of Palliative Care

• Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
Ruby Smith

• 70 year old woman
• Diagnosis: Metastatic Invasive Pancreatic Carcinoma
• Secondary Diagnoses:
  • Insulin-dependent diabetes mellitus
  • Osteoarthritis
  • Hypothyroidism
• Complications
  • Uremic gastritis
  • Obstructive jaundice
  • Acute on chronic renal failure (multifactorial)
• GOC: M1
Understanding Families

Family Systems Theory
Theory of human behavior that views the family as an “emotional unit”

- uses systems thinking to describe the complex interactions in the unit.

- It is the nature of a family that its members are intensely connected emotionally
Palliative Care & Family Systems

Family Systems Perspective

• Death and dying should be perceived as a family event
  • Reorganizes family roles, requiring adjustment of all family members
    Mehta et. al, 2009

• A change with one of the members of the family will influence the functioning of the entire system
Family Systems

• It is important to understand a family unit’s boundaries

  • Will impact how open/closed the family is to working with healthcare providers

  • Will determine the level of impact a team will be able to have on the family

(Mehta et. al., 2009)
Nursing Care Plan

• The use of a care plan can assist the nursing team with consistency of care, set expectations for the patient and family and assist with boundary setting.

• Care plans are often introduced when it has become clear that a more consistent approach is needed in order to provide adequate care to the patient and their family.

• Depending on the nature of the care determines the involvement of the patient and family in the creation of the plan.
Nursing Care Plan

• If related to direct patient care, for example personal/physical care, scheduling, medication administration, then it is often created with input with the patient and family.

• The charge nurse or the patient’s direct nurse would create a care plan with the family and boundaries and clear expectations would be set at that time

• All the nursing staff would adhere to the plan and therefore it is important that the expectations from the plan would be reasonable for all staff to follow
Care Plan for Mrs. Smith:

Personal Care:
- Patient’s morning care is to be completed after 1000
- Do not use SAGE wipes, patient has her own soap and lotion
- Please offer a shower on Tuesday and Thursday

Eating:
- Patient does not drink water, please offer own juices (no citrus) with ice
- No straws
- Set up meal tray and offer assistance to eat
Care Plan for Mrs. Smith: (con’t)

Medication:
- Oral medications with yogurt only (pt does not like applesauce or pudding and cannot take with only water)
- No subcutaneous sites on patient’s thighs

Environmental:
- Please open blinds and leave open for the day
- No flannel sheets as the patient gets too warm

• Any complaints about the care are not to be engaged by nursing staff, redirect their complaints to unit manager
Nursing Care Plan

• Care Plans relating to interacting with the patient and/or families are often drafted without the input of the patient or family but they need to be included on certain details (naming a spokesperson for example)

• It often includes communication techniques, specific boundaries, and simple responses

• These plans are helpful as they provide consistent messages and direction and limit team splitting behaviours by patients or families

• The care plans also provide staff with increased comfort when interacting with families and ensures them that they are providing a consistent message
Care Plan for Mrs. Smith

Communication:

- Communication is go through Mrs. Smith’s son Bruce and he has agreed that he will be contact person for the health care team and he will disseminate information to the rest of the family.
- If the patient’s daughter Nancy calls and is asking for information direct her to speak with her brother Bruce.
- If Nancy is being rude or abusive via the telephone inform her that it will not be tolerated and hang up the phone (this was as per patient relations direction).
Care Plan for Mrs. Smith

Communication with physician:

- If Nancy calls and demands to speak to a physician, inform her that they will not be returning her call and if she requires information she can speak to Bruce who is in contact with the medical team regularly.

- The physician will see the family once a day, unless reassessment is needed as perceived by the nursing staff. If the family is asking to see the physician after their rounds have been completed, remind them that the physician will return in the morning.
Nursing Care Plans

• The nature of the care plan will determine who carries it out
• Care Plans involving personal care are directed more towards the nursing staff
• Care Plans involving communication with family are made available to all members of the team as a consistent, unified approach is often the most successful
Nursing Strategies

• Caring for a patient and family who are struggling, regardless of how they express it, can be very challenging if possible rotating nursing assignments can be very helpful to ensure the same nurse isn’t always caring for them

• If a patient and family tend to require more time try to rearrange the workload to see if the nurse can have a lighter assignment in other ways

• Include other members of the team if possible. Volunteers, social worker, rehab, spiritual care can all provide support to the patients and families

• Debrief regularly
Red Flags For Needing Help

• Feeling de-skilled when dealing with an individual
• Multiple complaints
• Difficult diagnosis
• Inflexible attitude in communication style
• Other team members are having similar issues with the same individual
• Individual is verbally abusive, threatening
• Persisting personality conflicts
• Resident/patient/family members require a disproportionate amount of staff time
• Individual is resistant to unit or program protocols
Relate and Respond

**ReLATE**
Everyday tips for interacting with patients and families:

- **R.** Respect the dignity and privacy of the patient/family.
- **E.** Explain who you are and what you are going to do.
- **L.** Listen to what the patient/family is really saying.
- **A.** Ask questions to clarify what you have heard.
- **T.** Try to be flexible and offer alternatives.
- **E.** Empathize with the stress that accompanies illness.

**ReSPOND**
When you are the first to receive a complaint:

- **R.** Recognize the complainant’s perspective.
- **E.** Establish rapport with the complainant.
- **S.** Single out complainant’s real issues.
- **P.** Provide information to the complainant about what action you will take towards resolving his/her issues.
- **O.** Operationalize the indicated plan of action by completing steps yourself or forwarding as appropriate to your next level of management.
- **N.** Notify the complainant about the action you have taken towards resolving the concern.
- **D.** Discuss the circumstances of the concern with your next level of management if indicated. Document as appropriate.
De-escalating strategies

• Establish a consistent care plan
• Establish a team spokesperson
• Request the family develop a spokesperson
• Establish a time frame for updates
• Clearly identify treatment goals (link to ethics)
• Establish family roles/participation (may require limit setting)
Ethical and Moral Questions in Caregiving
Ethical and Moral Questions in Caregiving

• Is there a significant disagreement or difference of opinion between care team members or between the patient or family and the care team?
• Is there significant moral uncertainty about a particular patient's care plan?
• Are there conflicting views on the goals of care or the best interests of the patient?
• Do you need to weigh diverse moral values and beliefs or multiple options?
• Are there any clear standards of care, practice or policy that would resolve the issue?
If We Think It’s Futile, Can’t We Just Say No?

Care Team
• Needing to set limits to the treatments they are being asked to provide
• “Not in the patient’s best interest,” “prolong dying,” “prolong suffering”
• The treatment is futile
• Avoid or minimize harm, and commit to doing good

Family
• Difference of opinions about the kinds of treatments that are appropriate
• Underlying values, goals and life experiences

Futile with respect to what goal? And whose goal is that?
Summary of patients death

• The patient died peacefully on the unit. 3 of 4 children were present for her death and reacted appropriately and appeared to expect her death.

• Our care of the patient changed as the needs and expectations of her and her family changed. Nancy was demanding of both interventions and time and required setting strict boundaries and support for all disciplines on the unit.

• We involved patient relations and ethics who provided insight, strategies and confirmation of our instincts.
What would you do?
Organizational Resources Slide

- Manager
- Clinical Nurse Educator
- Spiritual Care
- Employee Assistance Program
- Critical Incident Stress Management
- Ethics
- Human Resources
- Occupational Health and Safety
- Protective Services
- Quality Consultants
- Library
- Patient Relations
- Interpretive Services
Questions or comments?
References/Resource Links

• Compassionnet.ca
  • Ethics Centre
    • https://www.covenanthealth.ca/ethics-centre.aspx
  • Patient Relations
    • https://www.compassionnet.ca/PatientResident/YourVoiceMatters-Poster.PDF
  • Employee Family Assistance Program
    • https://www.compassionnet.ca/Page385.aspx
  • Critical Incident Stress Debriefing
    • https://www.compassionnet.ca/Page615.aspx

• Insite.ca
  • Patient Relations
    • https://insite.albertahealthservices.ca/Page4738.aspx
  • Ethics
    • https://insite.albertahealthservices.ca/qhi/Page4875.aspx
  • Employee Family Assistance Program
    • https://insite.albertahealthservices.ca/hr/Page964.aspx
References


